

Missouri Planning Council
for Developmental Disabilities
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*Missouri Planning Council
for Developmental Disabilities*
2010 Annual Report

“Let People With Disabilities Live Real Lives”



The Missouri Planning Council for Developmental Disabilities is a federally-funded, 23 member consumer-driven council appointed by the Governor. Its mandate under P.L. 106-402, the Developmental Disabilities Assistance and Bill of Rights Act, is to ensure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity and integration in all aspects of community life.

The Council's Mission is *to assist the community to include all people with developmental disabilities in every aspect of life.*

The Council believes that mission will be achieved when people with developmental disabilities:

- make informed choices about where they live, work, play and worship;
- receive individual and family supports that are flexible, based on need, and provided in a culturally-sensitive manner;

- have the opportunity to engage in productive employment and meaningful retirement;
- experience continued growth toward their full potential;
- live in homes in the community with the availability of individualized supports;
- are treated with dignity and respect;
- attend neighborhood schools with their peers in regular classrooms, and
- are members of powerful advocacy networks made up of individuals, parents and family members.

The Council also believes that individuals, parents and family members are the most powerful forces in forging a responsive and flexible support network for people with developmental disabilities.

In order to meet our federal mandate, the Council must engage in advocacy, capacity-building and systems change efforts. The Council carries out their responsibility for advocacy under the Developmental Disabilities Assistance and Bill of Rights Act by serving

as an advocate for individuals with developmental disabilities and conducting or supporting programs, projects and activities that educate, advise, and inform policymakers. Capacity building occurs through council projects and activities that result in long-term changes in the service system that benefit people with developmental disabilities. The Council does not provide direct services but focuses their efforts on bringing best practices to Missouri that will lead to increased community capacity. We know that we have achieved systems change when we see sustainable, transferable and replicable change in some aspect of services or support availability, design or delivery that leads to positive or meaningful outcomes for people.

The Council focuses their advocacy, capacity building and systems change efforts on many different areas of emphasis supporting projects in housing, education, transportation, health, information and resources, research, and safety for individuals with developmental disabilities. While more extensive information is available on each of these project areas on the Council's web site www.mpcdd.com, for the purposes of this report, we will expand on our outcomes in the following areas:

What Are Developmental Disabilities?

Developmental Disabilities are physical or mental impairments that begin before the age of 22 and alter or substantially inhibit a person's capacity to engage in the everyday activities of life, including self care; communication; learning; mobility, or being able to work or live independently. *Developmental Disabilities* may include Down Syndrome, Cerebral Palsy, Autism, Mental Retardation and others. Over 100,000 Missourians experience developmental disabilities. This group of individuals is as varied as any other group of people. They go to school or work, have families and friends, nurture hopes and dreams and have expectations and potential.



EMPLOYMENT



Council Goal: Individuals have the opportunity to be successful in obtaining and maintaining integrated competitive employment.

We know from needs assessments and surveys that employment opportunities are very important to people with DD and that many individuals and their families feel these opportunities are very limited. Yet, when people with developmental disabilities succeed in obtaining a job in the community and share their story, we realize the impact of this simple thing that many take for granted.

To address this need, the Council funded three Organizational Change projects to provide agencies providing services to people with DD an opportunity to change from facil-

ity-based employment or day services to community employment. The Arc of the Ozarks, Springfield, is moving into its second year with three persons in their day program getting competitive community jobs and over 20 individuals participating in micro-enterprise. The conversion of the Arc's day programs was so successful that they shut down one of their day centers six months early. Triality, of Liberty, and Life Skills, of St. Louis, are completing the first year of their projects to convert day programs to community employment, and both projects continue to exceed expectations.

Because we know that finding a job sometimes is about who you know as much as what you know, the Council sponsored a project that developed a Career Discovery Guide that assists individuals in mobilizing their friends and family to help them find employment opportunities. A train-the-trainer program was developed to help employment providers learn this new way of doing business, and it has been piloted in several locations. The Career Discovery Guide has received local and national praise, and is widely used throughout the state by several school districts, Independent Living Centers, and VR offices as well as numerous supportive employment providers.

We know that, in Missouri:

- *Only 8% of people with DD who are served by the Division of Developmental Disabilities have competitive, community-based jobs while the national average is 19%*
- *Of the 50 states, MO ranks 48th in terms of competitive, community-based employment for individuals with DD*

QUALITY ASSURANCE



Council Goal: People are free of abuse, neglect, exploitation and violation of their human rights. They are self-determined and have opportunities for independence, productivity, integration and inclusion in the community.

This is a broad area of emphasis established by ADD to help Councils engage in efforts that improve the quality of life for individuals with developmental disabilities by improved services, prevention of abuse and neglect, protection of legal or human rights, and opportunities for training in leadership, self-advocacy and self-determination. The Missouri Council has supported multiple projects that address their Quality Assurance Goal.

[Guardianship] . . .

Many self-advocates tell us that they feel they have been robbed of their civil rights through Missouri's quick reliance on a full guardianship model. Family members express confusion regarding the process for obtaining guardianship and report being unaware of the options and alternatives to full guardianship that are available. Once they become aware of less restrictive ways to provide the protection and support their loved ones need, they often lack the financial resources to reverse the process. The Council supported a three-year Guardianship Project that had two primary components.

First, training was developed to help families improve their capacity to make informed choices as they consider and pursue guardianship options for their children. Training was provided across the state for over 270 individuals. The project will continue to track these families to determine the number of individu-

"In 1983, I had a car accident that caused my disability. ... after my father's death, people thought I would need someone to look after me so I was appointed a guardian. ... I lost my legal rights - all of them. Last year I went to an 'Alternatives to Guardianship' training. It made me want to ... win back my rights! ... I didn't need someone else to make decisions for me. ... I have my rights back!"

-- Mike Bishop

als who choose a less restrictive guardianship option or alternative, or pursue other avenues entirely. The Second Component focused on redetermination of guardianship and was designed to improve the capacity of self-advocates, their families and key supporters to make informed decisions related to their current guardianship status and to navigate systems to make desired guardianship changes. A curriculum was developed and training was conducted across the State. 270 individuals received training, and Missouri Protection & Advocacy Services, Inc., opened 65 legal cases.

While several cases continue to make their way through the legal system, 37 individuals had full or partial rights restored or were assigned a lesser form of guardianship. A guardianship resource guide was developed and is available on the Council's web site. An on-line training curriculum is being developed and the Council is leading an effort to explore the possibility of updating or amending the current guardianship statute.

Systems change occurred as Missouri P&A implemented new program practices including ongoing training, and an openness to working with individuals who express a desire to make

We know that, in Missouri:

- *There is a strong reliance on full guardianship with lesser forms of legal intervention such as limited guardianship or power of attorney often being overlooked*
- *In FY02-FY06, 30,680 full guardianships and only 349 limited guardianships were awarded*

Leadership Training . . .

Self-advocates and families struggle to navigate complex systems and access needed services. Many spend countless hours trying to find information and services that are available while waiting for services that truly meet their needs.

The Council provides leadership training for individuals with developmental disabilities and their families through support of Partners in



Policymaking. Partners is an innovative national model of leadership training designed for adults with developmental disabilities and parents of young children with developmental disabilities. The program teaches leadership skills and the process of developing positive partnerships with elected officials, school personnel and other individuals who make policy decisions about services that individuals with developmental disabilities use. Partners is about systems change -- creating, working towards, and achieving a vision of shared values about people with disabilities. It is based on the belief that the most effective and enduring public policy decisions are made by the people who need

and use services in partnership with elected officials and other policymakers. It is about becoming confident in oneself, competent in knowledge and information received, and comfortable in sharing the life experiences and expertise one brings to the program.

Missouri boasts 329 graduates and each year we see some remarkable accomplishments from their leadership skills. Partners were instrumental in dropping the "MR" from the name of the Division of Developmental Disabilities and securing the passage of Autism insurance legislation. Recently, one graduate used the knowledge gained through Partners to restore their rights with a reduction

What We Know:

- *57% of MO children with IEPs, ages 6-21, are inside the regular classroom at least 80% of the school day*
- *The rate of students with IEPs exiting from Special Education with a diploma is 71%, and the dropout rate is 27%*
- *Approximately 1.5% of the general population has developmental disabilities, yet they constitute 4-10% of the nation's prison population*
- *According to the National Crime Victimization Survey, people with DD experience nonfatal violent crimes at a rate 1.5 times higher than the rate for persons without disabilities*
- *Nearly 5,000 people with DD are waiting for services*
- *628 people with DD are living in MO institutions*
- *People with DD want to work in the community for real wages, but some reports show as few as 75% succeed in reaching this goal*
- *Only 340 of the nearly 30,000 individuals with DD served by the Division of DD, self-direct their services*

in guardianship. Others have developed an interactive web site as a resource for families of children with autism, written resource books for families, developed regional advocacy groups, and built parent advisory councils within their local school districts. Many of our graduates serve on local and state boards or committees that influence the services provided to people with developmental disabilities.

Advocacy . . .

While the Council carries out its responsibility for advocacy under the Developmental Disabilities Assistance and Bill of Rights Act through leadership trainings and support for projects such as Partners, the Developmental Disabilities Resource Center, and People First (MO's self-advocacy organization), it also meets this responsibility by demonstrating leadership in advocacy efforts. Members educate policymakers and build relationships with state decision makers to meet their state mandated advisory role.



The legislative list serve is used to inform people with DD, families and their allies of opportunities to provide input into the legislative process and making of public policy as well as to educate them about supportive or challenging policies that are being considered or implemented. This list serve provides information to over 600 Missourians.

The Council also provides leadership and support for bringing advocates from various organizations concerned with disabilities together to build a common message through the Congress on Disability Policy. Ten organizations are participating and representing over 100,000 stakeholders. Members and staff participate in various coalitions and committees to share their concerns and the

Council's philosophy about inclusion, integration, productivity and self-determination.

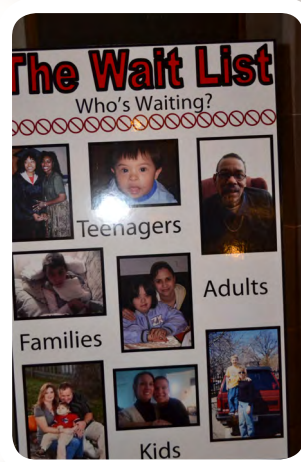
The Council exhibits leadership in organizing and carrying out Disability Rights Day that brings over 700 advocates to the state capitol to share their story

with legislators.

The Council has funded the Arc of Missouri to embark on a major project to increase awareness of the state's growing wait list. The Council funded a popular public

awareness campaign in March and worked with the Governor to proclaim March as Missouri's official DD Awareness Month. Posters about negative language were provided to Missouri's libraries, schools and others upon request. People First chapters used this effort to provide presentations to community groups. 2,500 posters were distributed along with bookmarks, postcards and silver ribbon pins.

The Council has focused much effort on building community capacity so that people who desire to transition away from segregated settings have increased opportunities in the community. To encourage professionals working with people with developmental disabilities and families to look closely at community options, the Council sponsored a webinar training regarding transition and a DVD of the successful transition of an individual who lived in one of the state's six institutions (ICF/MR) for over 50 years. Over 266 people participated in the webinar and hundreds of DVDs have been distributed.



THE DD COUNCIL...

During FY 2010, the Council invested \$1,295,330 in grants and projects that directly benefitted Missourians with developmental disabilities and their families. These funds are tied to specific outcomes that were identified by an extensive statewide needs assessment in such areas as education, employment, housing, transportation, quality assurance and community supports. From these investments, the Council also leveraged state and private funds totaling \$1,811,560.



The Missouri Planning Council for Developmental Disabilities is a unique entity bringing together people with diverse perspectives who are appointed by the Governor. Membership includes:

- people with developmental disabilities and their family members,
- representatives of state agencies and service providers, and
- advocates and other interested citizens.

Membership. . .

Paula Bonney, Waynesville (Parent)
Michael Brewer, Jefferson City
(Older American's Act Agency
Representative)
Stephanie Briscoe, Lathrop (Parent)
Dale Dowell, Mexico (Parent)
Susan Eckles, St. Louis
(Protection & Advocacy Agency
Representative)
Cathy Enfield, Independence
(Self-Advocate)
John Harper, Jefferson City
(Vocational Rehabilitation Agency
Representative)
Michelle Hoffmeister, Farmington
(Parent)
Allen Nelson, Bolivar
(Self-Advocate)
Brenda Niemeyer, Edina (Parent)
Mark Ohrenberg, Columbia
(Self-Advocate)
Douglas Riggs, Kirkwood (Parent)
Kit Stahlberg, Fredericktown
(Self-Advocate)
Jacqueline Swinnie, Ballwin (Parent)
Theresa Valdes, Jefferson City
(Title XIX Medicaid Agency
Representative)
Petrice Welch, Kansas City
(Parent)
Diana Willard, Joplin
(Self-Advocate)
Sharon Williams, Lee's Summit
(Parent)

Ad Hoc Members

Brent Blackwell, Carrollton
(Non-governmental/SB40 Board
Representative)
Wendy Dillender, Columbia
(Division of Developmental Disabilities
Representative)
Vim Horn, Kansas City
(University Centers for Excellence in DD
Representative)
Connie Koerner-Bean, Cape Girardeau
(Title V Agency Representative)
Jackie McKim, Jefferson City
(IDEA Agency Representative)

Staff. .

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Cathy Brown, Program Specialist
Geoffrey Lanham, Program Specialist
Charles Nickolaus, Program Specialist
Dolores Sparks, Program Specialist
Pamela Byars, Program Assistant
Dawn Kirchner, Sr. Office Support Assist.

Contact Us. .

Visit our web site at www.mpcdd.com and
join us in our efforts to bring changes to Mis-
souri.

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